

104TH CONGRESS  
1ST SESSION

# S. 1442

To authorize the Secretary of Health and Human Services to award a grant for the establishment of the National Center for Sickle Cell Disease Research, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

DECEMBER 4, 1995

Mr. JOHNSTON introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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## A BILL

To authorize the Secretary of Health and Human Services to award a grant for the establishment of the National Center for Sickle Cell Disease Research, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

### 3 SECTION 1. FINDINGS AND PURPOSE.

4 (a) FINDINGS.—Congress finds that:

5 (1) Sickle Cell Disease is a serious illness that  
6 disproportionately affects African-Americans.

7 (2) Approximately 1 out of every 12 African-  
8 Americans is born with the sickle cell trait, and

1 about 1 out of every 600 is afflicted with Sickel Cell  
2 Disease.

3 (3) Sickel cell conditions also occur in other  
4 United States populations, primarily those of Puerto  
5 Rican, Cuban, southern Italian ancestry and more  
6 recently sickel cell has been found in some Cauca-  
7 sian individuals.

8 (4) Sickel Cell Disease is a painful and dis-  
9 abling disorder which can lead to untimely death  
10 and is caused by inadequate transportation of oxy-  
11 gen due to an abnormal type of hemoglobin molecule  
12 in the red blood cells.

13 (5) Sickel Cell Disease is an inherited disease  
14 which can be transmitted to offspring, particularly if  
15 both parents carry the genetic trait.

16 (6) The sickel cell trait carriers show no sign of  
17 the disease, but statistically, 1 in 4 of their children  
18 will be afflicted with the disease.

19 (7) There is no national research center devoted  
20 to Sickel Cell Disease in the United States.

21 (8) There is no known cure for Sickel Cell Dis-  
22 ease at this time and there is a need for prioritized  
23 and specialized research to find such a cure for this  
24 severely disabling disease.

1           (9) Louisiana's minority population is  
2       1,299,281.

3           (10) Of this number, a suspected 3,248 individ-  
4       uals will have the disease and of those individuals,  
5       25 percent (812 individuals) will have the most  
6       acute and serious stage of Sickle Cell Disease, a  
7       stage that is usually fatal.

8           (11) Some 129,928 individuals in Louisiana will  
9       carry the sickle cell trait.

10          (12) Southern University, located in Baton  
11       Rouge, Louisiana is the largest predominately Afri-  
12       can-American university in the United States.

13          (13) Approximately 16,700 students attend this  
14       112 year old school and Southern graduates are lo-  
15       cated throughout the United States and the world.

16          (14) The State of Louisiana through the Lou-  
17       isiana Legislature and Southern University, has  
18       shown great leadership and committed significant fi-  
19       nancial and personnel resources towards the develop-  
20       ment of a National Center for Sickle Cell Disease  
21       Research.

22          (15) Because Southern University has commit-  
23       ted its resources and personnel to seeing this project  
24       through to its ultimate goal, finding a cure for Sick-  
25       le Cell Disease, and because of Southern Univer-

1       sity's large minority population it is appropriate to  
2       locate the National Center for Sickle Cell Disease  
3       Research at Southern University in Baton Rouge.

4       (b) PURPOSE.—It is the purpose of this Act to estab-  
5       lish a National Center for Sickle Cell Disease at Southern  
6       University in Baton Rouge, Louisiana, that will have the  
7       following objectives—

8               (1) to conduct biomedical research and clinical  
9       investigations designed to find a cure for Sickle Cell  
10      Disease;

11              (2) to conduct a wide variety of human behav-  
12      ioral studies designed to provide new knowledge  
13      about such issues as the effectiveness of various  
14      counseling and education methods, and techniques to  
15      improve coping skills on the part of patients and  
16      their families;

17              (3) to establish collaborative arrangements and  
18      joint research programs and projects with other  
19      Louisiana institutions of higher education, such as  
20      Louisiana State University Medical Centers at New  
21      Orleans and Shreveport and Tulane University Med-  
22      ical Center to conduct clinical trials on anti-sickling  
23      agents;

24              (4) to provide expanded opportunities for fac-  
25      ulty members at the institutions described in para-

graph (3) to publish in the three broad areas of  
basic biomedical research, psychosocial research and  
clinical research;

(5) to become a laboratory for training both  
graduate and undergraduate students in research  
methods and techniques concerning Sickle Cell Dis-  
ease; and

(6) to develop, promote and implement joint re-  
search projects with other public and private higher  
education institutions including teaching hospitals  
on Sickle Cell Disease.

**SEC. 2. NATIONAL CENTER FOR SICKLE CELL DISEASE RE-  
SEARCH.**

(a) GRANT.—The Secretary of Health and Human  
Services shall award a grant to the Louisiana Department  
of Health and Hospitals for the establishment and con-  
struction of the National Center for Sickle Cell Disease  
Research at Southern University in Baton Rouge, Louisi-  
ana, and for related facilities and equipment at such Cen-  
ter. Prior to the awarding of such grant, the State of Lou-  
isiana shall certify to the Secretary—

(1) that the State of Louisiana has provided  
not less than \$7,000,000 to support and operate  
such Center; and



1           (2) that the State of Louisiana has developed a  
2       plan to provide funds for the continued operation  
3       and support of such center.

4       (b) AUTHORIZATION OF APPROPRIATIONS.—There is  
5       authorized to be appropriated \$21,000,000 to carry out  
6       the purposes of this Act.

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